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Quality of Life and Pain Experienced by Children and Adolescents with Cancer at Home Following Discharge from the Hospital

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Abstract

An exploratory study was conducted to examine quality of life and pain experienced by pediatric cancer patients at home following discharge. Physical, cognitive, social, and emotional aspects of quality of life were measured, and how these may be affected by age, gender, diagnosis, and pain status. We also characterized intensity, location, and quality of pain experienced. A sample of 33 patients participating in a larger study was selected based on having pain on day of discharge, and having completed the Pediatric Quality of Life Inventory Generic, Cancer Module, Multidimensional Fatigue Scale, and the Adolescent Pediatric Pain Tool at home. Cancer diagnoses were leukemias/lymphomas (42.4%), brain/CNS tumors (27.3%), sarcomas (24.2%), or other (6.1%). More than half of patients reported pain (n=17; 51.5%). Patients with pain had more fatigue affecting quality of life (p=0.01), and lower physical and emotional functioning, leading to lower overall HRQOL scores (p=0.011). Females and adolescents reported worse emotional functioning (p=0.02 and p=0.05, respectively). Physical, cognitive, and social functioning was lowest among patients diagnosed with sarcomas (p=0.00, p=0.01, and p=0.04, respectively). It is important to understand the symptom experience of patients at home as a first step in moving towards optimal discharge teaching and treatment.

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Conflicts of Interest

The other authors have no conflicts of interest to disclose.

Keywords

Children; cancer; quality of life; pain

INTRODUCTION

An estimated 40,000 children undergo treatment for cancer in the United States each year.¹ Advances in therapeutic regimens have resulted in improved chances for survival, while changes in the healthcare system have enabled pediatric cancer patients to spend less time in the hospital environment and more time at home.² However, side effects such as pain, anxiety, fatigue, and alterations in physical, cognitive, social, and emotional functioning continue to impact overall quality of life for these patients throughout the course of their treatment.³

Pain is a potentially debilitating side effect associated with cancer treatment, although very little is known about how it affects quality of life in children after discharge from the hospital. Jacob and colleagues (2007) evaluated the pain experience of hospitalized children with cancer and found that more than half of patients experienced significant pain.⁴ Wang et al. reported that disease- and treatment-related causes of pain were most often attributed to bone metastasis (60%), postoperative pain (57%), oral mucositis (55%), or metastasis to the central nervous system (43%).⁵ Ljungman and colleagues found that out of 55 children and adolescents with cancer, 49% experienced “severe pain” which was treatment-related (e.g. limb, abdominal, and anal pain, mucositis, dyspepsia, and conjunctivitis); 38% experienced “moderate pain” that was procedure-related (e.g. bone marrow aspirations, injections, and venipunctures), and 13% reported “less severe pain” which was related to the disease process.⁶ While previous research has shown that pain negatively affects quality of life, impedes cancer recovery, contributes to patient and family distress, and is associated with long-term morbidity,⁷ there is limited understanding of the pain experiences of young patients at home (pain intensity, location, quality, and relief from medications), and domains of quality of life are not impacted.

The World Health Organization (WHO) aims to develop effective symptom management strategies⁸, but this effort must be informed by a thorough understanding of a patient’s symptom experience and affected health-related quality of life (HRQOL) outcomes. A major barrier in children with cancer is underreporting or misunderstanding of symptoms.^{3,9} Careful, systematic assessment and documentation of symptoms is required for adequate management.¹⁰ While symptoms are routinely assessed and managed during hospitalization, very little is known about how to characterize symptoms that manifest after discharge.^{11,5} Many studies that have evaluated side effects in children with cancer have taken place mainly in the clinic or hospital setting^{3,12} and often describe parental perceptions of their child’s condition. Very little is known about how symptoms are experienced by children themselves and how these affect quality of life in the home environment. Finally, there is limited knowledge regarding the degree to which demographics (age, gender), clinical information (diagnosis or reason for hospitalization), and symptoms might affect quality of life in this population.^{13,14}

The primary purpose of this exploratory study was to examine the quality of life and pain experienced by pediatric cancer patients at home following discharge. We evaluated physical, cognitive, social, and emotional aspects of quality of life, and how these may be affected by age, gender, diagnosis, and the pain status. The secondary aim of this project was to characterize the intensity, location, and quality of pain experienced at home. We hope that a better understanding of home symptomatology in this population will inform teaching and preparation for discharge.

MATERIALS & METHODS

Design

This exploratory study used a longitudinal, descriptive design. We selected a sample of children and adolescents with cancer who were participating in a larger study that examine pain, symptoms, sleep, and quality of life of pediatric cancer patients at home. 58 patients were screened and 33 children and adolescents were selected based on an indication that they had pain at time of discharge from the hospital, and they had completed the Health-Related Quality of Life Scale (PedsQL™ Gener, Cancer, Multidimensional Fatigue Scale) and the Adolescent Pediatric Pain Tool (APPT). Data from the third day following discharge from the hospital was used, when patients were expected to have re-acclimated to the home environment.

Population & Setting

Patients were recruited prior to discharge from two pediatric oncology acute care units in urban areas of Southern California. Patients were included if 1) age was 8 to 17 years, 2) planned discharge from the hospital was occurring within 48 to 72 hours, 3) children and parents could speak and read English, 4) child could give assent and a parent or legal guardian was available to give consent. Patients were excluded if 1) parents were not available at bedside to consent, and 2) the patient was too ill (including recent relapse) or had a prior history of neurological impairment, visual, hearing, or motor function deficit, or developmental delay that would prevent completion of study procedures. The Decision Making Tool was used to assess cognitive ability.

The sample of 33 out of 58 patients enrolled in the study over a two-year period was selected based on the criteria that the patients had indicated pain on day of discharge, and all had complete datasets for the outcome measures (APPT, PedsQL™ Cancer module and Multidimensional Fatigue Scale). A post-hoc sample size calculation was performed using Post Hoc Power Calculator (<https://clincalc.com/stats/Power.aspx>), indicating that a total sample size of 33, power of 0.80, with 0.05 alpha, was able to detect a 20% difference in mean Total HRQOL scores between those patients who did not have pain (n=16; mean Total HRQOL 86 ± 12.9), and those who continued to have pain (n=17; mean Total HRQOL 68.0 ± 22.3) on day 3 at home (Total HRQOL-Generic data from Table 2).

Recruitment & Enrollment

Approval was obtained by the Institutional Review Boards at University of California-Los Angeles, Children's Hospital of Los Angeles, and Children's Hospital of Orange County.

Advanced Practice Registered Nurses (APRNs) who were part of the pediatric oncology inpatient team were consulted about potential participants. The APRNs provided eligible patients and their parents or legal guardians with an information flyer that described the study, provided details, and addressed common questions. If there was interest in the study, the APRNs obtained consent from the parents or legal guardians, and assent from the child prior to enrollment.

Procedures

The APRNs instructed the children to complete the APPT at home each evening for a maximum of five days. Children and parents were told to bring the completed materials to their subsequent clinical appointment, which occurred five to seven days after discharge from the hospital. At this point, the APPT responses were gathered by the APRN, and the PedQL was administered. All questionnaire responses were entered into a statistical program (SPSS version 20.0) for analysis by the research assistant. Original documents were stored for a period of 60 months following completion of the study in a locked cabinet in a private office, then shredded.

Measurement Instruments

A demographic sheet was used to collect demographic information (age, gender, and ethnicity) and medical information (cancer diagnosis, reason for hospitalization) prior to discharge from the hospital. The date and time of the subsequent clinic visit was also recorded. The Pediatric Quality of Life Inventory (PedsQL™ Cancer Module and Multidimensional Fatigue Scale) was used to measure quality of life.^{15–18} The age appropriate, self-report versions were used for 1) children 8 to 12 years and 2) adolescents 13 to 17 years. The PedsQL™ was used to measure the core physical, mental, and social health dimensions. The items consisted of questions related to how much of a problem each item was the previous day (0=never a problem; 1=almost never a problem; 2=sometimes a problem; 3=often a problem; 4=almost always a problem). Items were reverse-scored and linearly transformed to a 0 to 100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Higher PedsQL™ scores indicate better HRQOL. The internal consistency reliability for child self-report and parent proxy report ranged from 0.66 to 0.93; the parent/child concordance intercorrelations ranged from 0.305 to 0.944.^{14–19–21}

The PedsQL™ 3.0 Cancer Module is disease-specific and consists of items representing four dimensions of quality of life: 1) Physical (pain, hurt, nausea); 2) Emotional (anxiety related to procedure, anxiety related to treatment, worries); 3) Cognitive (paying attention, remembering, problem solving); and 4) Social (perceived physical appearance, communication).¹⁵ The administration and scoring of the PedsQL™ Cancer Module was similar to the PedsQL™ Generic as described above, with lower scores indicating lower HRQOL.¹⁵

The PedsQL™ Multidimensional Fatigue Scale (MFS) consisted of three sub-scales assessing general fatigue, sleep/rest fatigue, and cognitive fatigue, with six items representing each.¹⁵ The responses consisted of questions related to how much of a problem each item posed (0=never a problem; 1=almost never a problem; 2=sometimes a problem;

3=often a problem; 4=almost always a problem). Scoring was similar to the PedsQL™ Generic as described above, with lower scores indicating that fatigue was often or almost always a problem. Internal consistency reliability and construct validity for the PedsQL™ MFS was established previously.^{15,18}

The Adolescent Pediatric Pain Tool (APPT) measured the intensity, location, and quality of pain. These three dimensions of the APPT have been validated for children and adolescents 8 to 17 years. Numerical Rating Scales (0 to 10) are used within the “Intensity” dimension of the APPT to quantify “How much pain 1) *do you have right now*” (current pain), 2) *the highest pain was during the day* (worst pain), and 3) *the lowest pain was during the day* (least pain).^{14,19,21} The validity and reliability of the Numerical Rating Scale was previously established with $r=0.66$ to $r=0.80$.^{14,22–23} Sensitivity to changes in pain ratings over time in children with medical/surgical conditions showed moderate correlations among pairs of scores between the APPT and the Numerical Rating Scale from $r=0.68$ to $r=0.97$, supporting convergent validity of the pain intensity dimension of the APPT and the Numerical Rating Scale. Test-retest reliability showed high correlations of $r=0.91$ between the two pain intensity ratings.^{14,19,21}

The APPT also contained a Body Outline Diagram (BOD; front body and back body), which was segmented into 43 areas for marking the “Location” dimension of pain.^{19,21} The APPT provides a scoring template for quantifying the number of pain sites (0 to 43 sites), as a measure of pain location marked on the BOD.^{19,21} Savedra, and colleagues^{19,21} tested the BOD for measurement of pain location in hospitalized children and adolescents (8 to 17 years) who had postoperative pain, and found the inter rater agreements between 1 to 3 pairs of coders were good with $k = 0.58$ to 0.71 on site number and surface area covered, supporting the reliability and validity of the BOD.

Finally, the pain “Quality” dimension was described within the APPT utilizing a list of 56 words that categorized sensory (0–37), affective (0–11), evaluative (0 to 8), and temporal (0 to 11) aspects of pain.^{19–23} Wilkie and colleagues^{20,22} tested the measurement of pain quality using the pain word descriptors list of the APPT in postoperative children and adolescents. They found significant correlations between the number of 1) sensory words and number of BOD pain areas ($r=0.99$); 2) affective words and number of BOD pain areas ($r=0.81$); 3) evaluative words and number of BOD pain areas ($r=0.99$); 4) temporal words and number of BOD pain areas ($r=0.86$), and 5) sensory, affective, and evaluative word scores ($r=0.63$ to 0.66), supporting the reliability and validity of the pain word descriptors.

Statistical Analysis

A statistical program (SPSS® version 20.0) was used to enter all data, and entries were double checked by two research assistants. Independent samples t-tests were used to examine differences in quality of life domains based on age, gender, and pain status. Analysis of variance (ANOVA) was used to examine differences across quality of life domains by diagnosis (leukemia/lymphoma, sarcoma, or other cancer diagnosis) and reason for hospitalization (chemotherapy, fever/neutropenia/infection, or other reason for hospitalization). Descriptive statistics (mean, standard deviation, frequencies) were used to

summarize pain intensity (numerical rating from 0 to 10), location (number of pain areas on the BOD), and quality (the number of sensory, affective, evaluative, and temporal scores).

RESULTS

There were 15 children and 18 adolescents who participated in the study with complete data sets for quality of life measures (PedsQL™ Cancer Module) and pain (APPT). Approximately half of the participants (Table 1) were Hispanic (48.5%), while the remainder were Caucasian (33.3%), or Other (18.2%). The most frequent diagnoses (Table 1) were leukemia/lymphomas (42.2%) or brain/CNS tumors (27.3%), which included medulloblastoma, ependymoma, and primitive neuroectodermal tumor. The others had sarcomas (24.2%), which included osteosarcoma, Ewing sarcoma, or rhabdomyosarcoma. One participant had an ovarian tumor and another had a germ cell tumor. The patients were hospitalized (Table 1) for chemotherapy treatment (54.5%), fever/neutropenia (27.3%), or other (18.2%), including diagnostic work-up, malnutrition, vomiting, diarrhea, or dehydration.

Quality of Life

Differences were found in the PedsQL™ Generic mean scores between patients with and without pain across the physical ($p=0.017$), emotional ($p=0.028$), and total HRQOL scores ($p=0.011$), indicating a lower quality of life in patients with pain (Table 2). There were significant differences in PedsQL™ MFS mean scores between patients with and without pain for sleep/rest fatigue ($p=0.005$), cognitive fatigue ($p=0.05$), and total fatigue ($p=0.01$).

No significant difference was found in PedsQL™ Generic scores between children and adolescents (Table 3). Although there were no significant differences in the subscale scores by age, the physical subscale was low for both children (72.2 ± 26.7) and adolescents (60.9 ± 31.4), indicating that this population generally experiences a low level of energy and decreased ability to perform physical activities, bathe, and do chores at home. Adolescents had lower scores on the emotional subscale of the PedsQL™ Cancer compared to children ($p=0.05$), indicating that they tend to experience more anxiety related to procedures; fear of treatments. Adolescents also had significantly lower scores in general fatigue (60.4 ± 30.2 vs 82.5 ± 22.8 , $p=0.02$), sleep/rest fatigue (60.4 ± 23.6 vs 76.9 ± 16.4 , $p=0.03$), and total fatigue (65.8 ± 24.4 vs 82.2 ± 13.9 , $p=0.02$), but not cognitive fatigue ($p=0.18$) in the PedsQL™ MFS.

Female patients had a significantly lower emotional subscale scores in the PedsQL™ Generic and PedsQL™ Cancer compared to their male counterparts (Table 3). Additionally, females had significantly lower scores in all of the fatigue subscales of the PedsQL™ MFS (Table 3).

Based on diagnosis, social subscale scores in the PedsQL™ Generic were lower for sarcomas and leukemia/lymphoma compared with brain/CNS and other diagnoses (Table 4). Patients with sarcomas also had significantly lower physical, cognitive, and total scores in the PedsQL™ Cancer (Table 4), indicating overall lower quality of life. This diagnosis had more problems with general fatigue in the PedsQL™ MFS compared to other cancer

diagnoses (Table 4), although the total fatigue score did not differ significantly across the various diagnoses (Table 4). There were no significant differences in the PedsQL™ scores by reason for hospitalization.

Pain Intensity, Location, and Quality

We found that the majority of patients experienced pain (51.5%) at home, which was characterized as mild pain (33.3%) or moderate to severe pain (18.2%) that fluctuated during the day. Patients who reported pain more frequently were adolescents (76.5%, $p=0.003$), with diagnoses other than leukemia or lymphoma ($p=0.032$), and who were admitted for Chemotherapy ($p=0.029$), as indicated in Table 1. The most frequently marked location of pain on the body outline diagram (Table 5) was the head and neck, followed by the chest, abdomen, lower back, and extremities. Pain was described as having different sensory, evaluative, affective, and temporal qualities (Table 5 and Figure 1). Sensory words describing pain included: *sore*, *sharp*, and *hurting*. Evaluative descriptors included the words: *uncomfortable*, *annoying*, and *bad*. Affective words included *awful*, *terrifying*, and *dizzy*, while temporal qualities were: *off and on*, *comes and goes*, and *continuous*. Pain descriptors from the evaluative and temporal categories were used more frequently than those in the sensory and evaluative categories.

DISCUSSION

We examined the physical, cognitive, social, and emotional aspects of quality of life as experienced by pediatric cancer patients at home following discharge for the first time. We evaluated how these HRQOL domains may be affected by age, gender, diagnosis, and the presence of pain. We also characterized pain intensity, location, and quality of pain among this population in the home setting. We found that the majority of cancer patients experienced pain at home, which is consistent with previous studies.^{5,8} While sensory words were commonly used to describe pain in previous inpatient studies,^{5,6,8} our findings indicate that patients at home select more evaluative and temporal pain descriptors. It is possible that pain experienced at home may differ from pain experienced during hospitalization, which is mostly procedure-related. Patients may have more distractions after discharge, as they interact with family in the comfort of their own homes, which may explain the evaluative and temporal pain quality descriptors. As in previous studies, the most frequent pain locations were in the head, abdomen, chest, lower back, legs, and feet.^{3,8,24}

Our findings also indicate that females are more likely to experience pain. The evidence regarding gender differences in patient pain response is mixed, as some studies report females to have an increased response to pain,^{26,10} while others report no difference according to gender.^{24–26} Coffelt and colleagues²⁷ reported that female patients experience more pain not only in cancer but also other conditions (e.g. sickle cell disease, burns). Our study shows that, in addition to pain, females report significantly lower emotional and fatigue scores related to quality of life. This finding is consistent with another study reporting that female patients with chronic pain have more depression- and anxiety-related issues accompanying their disease process.²⁸ Although results are mixed and it is difficult to draw conclusions, gender differences do seem to play a role in pain experiences and quality

of life measures, which may be attributed to “biological” and “psychosocial” mechanisms.²⁶ However, because of the small sample size of males and females in our study, it is possible that our findings related to differences may have occurred by chance, and therefore must be verified with larger samples. Paller and colleagues³⁰ reported that there are psychosocial factors (e.g. pain-related catastrophizing, hormonal effects) that may have significant impact on female pain perception and analgesic response, and which could inform the development of targeted and individualized treatment options based on gender as more data is obtained on this subject.

Similar to our findings, Smith and colleagues²⁹ reported that patients with sarcoma had lower HRQOL. It is possible that patients with sarcoma experience worse symptoms that negatively affected their quality of life²⁹ most notably with lower physical and cognitive functioning. Our results indicated that 35% of our patients with pain were diagnosed with malignant brain or CNS tumors which are usually fast-growing and invade surrounding tissues, thus contributing to neurologic deficits, altering pain and sensory perception, decreasing cognitive function, and thereby affecting HRQOL.^{31,32} Given the small number of patients included in this descriptive study, strong claims regarding the correlation between diagnosis and quality of life cannot be made without further hypothesis-testing through a quantitative approach.

It is interesting to note that the reasons for hospitalization did not have significant effects on HRQOL, which is probably due to the small sample size. Several studies have documented that different types of chemotherapy have different effects on HRQOL in children and adolescents with cancer.³³ While the analysis at day 3 at home may be representative of quality of life in general, there may have been patients who received cis-platinum in the hospital, and therefore had increased nausea at home during this time. This could have affected their PedsQL scores, although the symptom would have resolved at home one or two weeks later. Our findings, are consistent with others who reported that HRQOL were one to two standard deviations below the healthy population for all summary scores and dimensions, and lower in children receiving treatment for ALL compared to children with ALL at 12 months off therapy.^{34,34} Others have also noted problems with fatigue, detrimental effects of treatment on physical activities, and difficulties with social interactions, which might also affect HRQOL.^{36,37}

A major limitation in this study is the small sample size. Future studies with a larger sample including a variety of diagnoses are needed to examine pain experiences and possible consequences for HRQOL in the home or school setting. Findings from our study may be used for power calculations in future studies, or to inform future hypotheses about the possible predictors of pain or poor HRQOL at home following discharge in order to identify patients who are at risk during hospitalization. These additional research questions should be explored using a larger sample size and an investigative approach rather than a descriptive one. We selected patients based on their report of experiencing pain at the time of discharge, since our goal was to characterize their pain experiences during transition back to the home environment. However, this may have created a biased sample, since it is possible that patients who don't report pain at the time of discharge still experience pain after being sent home. Additionally, the measures used were only available in English, and therefore, our

study did not reflect the symptom experiences of children from other cultures who speak different languages. Thirdly, patients with neurological/sensory impairments were excluded, and it is possible that their pain experiences and quality of life may be different. Lastly, we did not collect information from parents, and we excluded children younger than 8 years old, who may have different symptom experiences in the home.

While pain is often assessed and reassessed around the clock during hospitalization, the experience of pain at home may not be monitored or adequately managed. This was the first study to explore and characterize pain intensity, location, and quality among pediatric cancer patients at home, and the differences in HRQOL when they had pain. Our findings should encourage providers to teach patients and families about monitoring pain and overall well-being at home, since a young patient's experience of these can vary significantly. Strategies for pain management should be suggested for all patients with a tailored approach. For example, additional emphasis should be placed on strategies for regulating emotional distress and fatigue among adolescents and females. Patients diagnosed with sarcomas might benefit from recommendations for maintaining physical and cognitive function in the home to improve overall HRQOL. Future studies are needed to examine the effects of tailored non-pharmacological or teaching interventions in improving pain management and overall quality of life outcomes in children and adolescents with cancer at home.

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Figure 1--.

Pain location in the APPT -- dark blue areas indicate the most frequently marked in 50% or more of the APPT entries.

Table 1.**Demographics**

	No Pain (N=16) n (%)	Pain (n=17) n (%)
Age		
Children	11 (68.8%)	4 (23.5%)
Mean Age	10.0 ± 1.4 years	10.5 ± 1.7 years
Adolescents	5 (31.3%)	13 (76.5%)
Mean Age	14.2 ± 0.8 years	15.08 ± 1.6 years
Gender		
Male	11 (68.8%)	5 (29.4%)
Female	5 (31.3%)	12 (70.6%)
Ethnicities		
Caucasian	6 (37.5%)	5 (29.4%)
Hispanics	7 (43.8%)	9 (52.9%)
Other	3 (18.8%)	3 (17.6%)
Cancer Diagnoses		
Leukemias/Lymphomas	9 (56.3%)	5 (29.4%)
Brain/CNS	3 (18.8%)	6 (35.3%)
Sarcomas	3 (18.8%)	5 (29.4%)
Other	1 (6.3%)	1 (5.9%)
Reasons for Hospitalization		
Chemotherapy	7 (43.8%)	11 (64.7%)
Fever & Neutropenia	7 (43.8%)	2 (11.8%)
Other	2 (12.5%)	4 (23.5%)

Table 2.**Pain & Quality of Life**

	No Pain (n=16)	Pain (n=17)	P-Values
PedsQL Generic			
Physical (<i>Walking, Exercise, Lifting</i>)	78.4 ± 21.5	54.4 ± 31.8	0.02 *
Emotional (<i>Sad, Angry, Worry</i>)	92.5 ± 11.7	76.5 ± 25.3	0.03 *
Social (<i>Peers, Friends</i>)	88.8 ± 14.4	78.5 ± 18.4	0.09
Total HRQOL-Generic	86.0 ± 12.9	68.8 ± 22.3	0.01 *
PedsQL Cancer			
Physical (<i>Pain, Nausea</i>)	78.2 ± 27.9	64.1 ± 28.5	0.17
Emotional (<i>Anxiety, Worry</i>)	82.0 ± 27.7	76.0 ± 22.8	0.50
Cognitive (<i>Attention, Memory, Problem Solving</i>)	79.6 ± 30.2	81.2 ± 16.5	0.85
Social (<i>Appearance, Communication</i>)	91.4 ± 12.0	85.3 ± 20.5	0.31
Total HRQOL-C	86.0 ± 12.9	68.8 ± 22.3	0.29
PedsQL Cancer Related Fatigue			
General Fatigue (<i>tired, weak, trouble starting/finishing things</i>)	79.4 ± 28.4	62.0 ± 27.5	0.08
Sleep/Rest Fatigue (<i>sleeping a lot, tired waking up, resting/napping a lot</i>)	78.6 ± 14.2	57.8 ± 23.5	0.01 *
Cognitive Fatigue (<i>hard paying attention, hard remembering, trouble thinking</i>)	89.6 ± 11.9	73.8 ± 29.0	0.05 *
Total Fatigue	82.5 ± 14.4	64.5 ± 24.1	0.01 *

*
p<0.05

Table 3.

HRQOL by Age & Sex

	AGE		SEX	
	Children (n=15)	Adolescents (n=18)	Males (n=16)	Females (n=17)
PedsQL Generic				
Physical	72.2 ± 26.7	60.9 ± 31.4	73.4 ± 24.8	59.1 ± 32.5
Emotional	91.0 ± 13.9	78.6 ± 24.8	91.6 ± 13.0	77.4 ± 25.3
Social	84.7 ± 17.5	82.5 ± 17.3	88.4 ± 13.0	78.8 ± 19.6
Total	82.0 ± 17.5	73.2 ± 21.7	83.8 ± 13.8	71.0 ± 23.3
PedsQL Cancer				
Physical	79.8 ± 24.8	63.5 ± 30.4	79.0 ± 22.5	63.3 ± 32.5
Emotional	87.9 ± 12.4	71.3 ± 30.5	89.2 ± 10.7	69.2 ± 30.8
Cognitive	82.7 ± 22.1	78.5 ± 25.6	86.3 ± 20.2	74.9 ± 26.1
Social	88.3 ± 16.9	88.2 ± 17.5	90.9 ± 15.8	85.8 ± 18.0
Total	84.9 ± 13.3	74.0 ± 22.0	86.4 ± 11.6	72.0 ± 22.3
PedsQL Fatigue				
General	82.5 ± 22.8	60.4 ± 30.2	81.7 ± 21.8	59.8 ± 31.3
Sleep/Rest	76.9 ± 16.4	60.4 ± 23.6	76.8 ± 15.5	59.6 ± 24.2
Cognitive	87.2 ± 13.8	76.6 ± 28.8	93.8 ± 11.2	69.9 ± 26.3
Total	82.2 ± 13.9	65.8 ± 24.4	84.1 ± 12.1	63.1 ± 24.0

* Significant at p < 0.05

Table 4.

HRQOL by Cancer Diagnoses & Reasons for Admissions

	CANCER DIAGNOSES				REASONS FOR ADMISSION						
	Leukemia	Lymphomas	Brain/CNS Tumors	Sarcomas	Other	p values	Chemotherapy	Fever	Neutropenia	Other	p values
PedsQL Generic											
Physical	76.2±27.4		63.0±28.7	45.3±27.0	91.7±11.8	0.06	62.5±31.1	75.9±25.0	61.8±32.2		0.51
Emotional	87.5±17.7		87.2±10.0	73.8±34.5	90.0±0.00	0.47	82.5±25.3	88.3±16.6	83.3±14.7		0.80
Social	86.8±16.7		89.4±7.7	68.8±20.1	92.5±10.6	0.04*	81.9±18.1	86.1±19.2	84.2±12.8		0.84
Total	83.0±18.7		78.8±14.4	61.5±23.1	91.4±7.7	0.06	74.8±21.9	83.0±19.2	75.5±16.6		0.61
PedsQL Cancer											
Physical	86.5±13.5		73.8±24.0	37.3±27.3	94.6±2.5	0.00*	65.2±34.1	82.9±18.7	70.2±20.8		0.33
Emotional	82.3±19.0		85.5±9.7	65.0±42.5	80.4±4.1	0.36	78.9±30.3	86.1±14.8	68.1±18.2		0.41
Cognitive	89.6±12.5		81.1±12.9	58.5±35.7	100.0±0.00	0.01*	77.9±29.5	82.2±16.8	85.0±12.2		0.80
Social	90.8±13.0		87.0±20.0	82.8±21.5	97.9±2.9	0.63	88.2±20.0	89.4±10.8	86.8±16.8		0.96
Total	85.7±11.7		82.0±11.2	60.6±27.2	91.6±1.4	0.01*	76.8±23.9	85.3±11.6	75.9±9.1		0.52
PedsQL Fatigue											
General	78.6±25.0		73.1±22.2	46.9±33.6	95.8±5.9	0.04*	66.0±31.9	87.0±19.0	59.0±24.0		0.11
Sleep/Rest	69.6±17.4		67.6±28.3	58.3±19.7	95.8±5.9	0.18	70.4±24.0	69.9±14.1	57.6±25.5		0.46
Cognitive	89.3±13.8		79.6±27.1	67.2±30.3	91.7±11.8	0.18	80.8±26.7	87.0±12.0	75.0±27.9		0.63
Total	79.2±16.1		73.4±24.4	57.5±22.3	94.4±7.9	0.06	72.4±24.1	81.3±13.2	63.9±23.0		0.31

* Significant at p <0.05

Table 5.**Pain Location, & Quality (N=17)**

	n (%)
Pain Location	
Head & Neck	6 (36.7%)
Chest	4 (23.5%)
Abdomen	4 (23.5%)
Low Back	4 (23.5%)
Extremities	4 (23.5%)
Pain Quality	
<u>Sensory</u>	
Sore	7 (43.3%)
Sharp	6 (36.7%)
Hurting	5 (33.3%)
<u>Evaluative</u>	
Uncomfortable	11 (66.7%)
Annoying	9 (56.7%)
Bad	5 (26.7%)
<u>Affective</u>	
Awful	5 (26.7%)
Terrifying	3 (16.7%)
Dizzy	2 (13.3%)
<u>Temporal</u>	
Off and on	8 (50.0%)
Comes and goes	7 (43.3%)
Continuous	6 (36.7%)